DOCUMENT RESUME

ED 314 648 CG 022 178

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TITLE	Health Professionals and the Bereaved.
INSTITUTION	Institute of Medicine (NAS), Washington, D.C.
SPONS AGENCY	National Inst. of Mental Health (DHHS), Rockville, MD.
REPORT NO	DHHS-(ADM)88-1552
PUB DATE	88
NOTE	55p.; For related documents, see CG 022 179-180.
PUB TYPE	Guides - General (050) -- Reports - General (140)
EDRS PRICE	MF01/PC03 Plus Postage.
DESCRIPTORS	Adults; *Age Differences; Children; Coping; *Death; *Emotional Adjustment; Emotional Response; *Family Problems; *Health Personnel; Social Support Groups
IDENTIFIERS	*Bereavement

ABSTRACT

Based on the premise that health care providers and institutions have a professional obligation to help bereaved families, this booklet focuses on the role of health care professionals in lessening distress, helping prevent pathological outcomes, and assisting the bereaved toward a satisfactory outcome. The information provided in this guide is especially designed to alert health care professionals to signs among the bereaved that warrant referral to a mental health professional. A section on adult bereavement looks at the phases of bereavement reactions and the end of the bereavement process, identifies those who may be at risk following bereavement, and discusses the need for professional intervention. The section on children and bereavement examines children's fears, fantasies, and behavior and identifies children at risk for poor outcomes. Roles of health professionals working with the bereaved are identified, the special problems associated with sudden death are considered, and the continuing responsibilities of health professionals are discussed. The next section addresses cautions about the use of medications for bereavement reactions. A section on community resources addresses the issues of lay versus professional help, characteristics of bereaved clientele, and the timing and impact of bereavement interventions. References are included; support group information is appended. (NB)

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health professionals and the bereaved

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The information in this booklet has been adapted from an Institute of Medicine, National Academy of Sciences, study report *Bereavement: Reactions, Consequences, and Care*, Marian Osterweis, Fredric Solomon, and Morris Green (eds), 1984. The full report is available from:-

National Academy Press
2101 Constitution Avenue, N.W.
Washington, D.C. 20418

The original study and preparation of this manuscript were supported by contracts from the National Institute of Mental Health of the Alcohol, Drug Abuse, and Mental Health Administration, U.S. Department of Health and Human Services.

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DHHS Publication No. (ADM) 88-1552
Printed 1988

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INTRODUCTION

Every year an estimated 8 million Americans experience the death of an immediate family member, and an unknown number experience the death of other important relatives and close friends. Every year there are 800,000 new widows and widowers. Suicide occurs in at least 27,000 families each year (and probably many more since suicide is underreported). Each year approximately 400,000 persons under the age of 25 die. Only those who die young escape the pain of losing someone they love through death. Just as each type of relationship has special meaning, so too does each type of death carry with it a special kind of pain for those who are left behind.

Bereavement is usually considered to have the most powerful impact of all stressful life events. In addition to feelings of grief and emotional distress, perturbations in physiologic functioning and interpersonal relations are very common. To be bereaved has been likened to being an immigrant in a foreign country—social relationships are altered, expectations for behavior are unclear, and one is generally disoriented. The established rhythms of everyday life are likely to be upset.

As with many other stressors, the consequences of bereavement are not the same for everyone; many factors can modify that stress and affect long-term outcomes. The sudden and unexpected suicide of a young husband and father, for example, is likely to have much more profound effects on

surviving family members than the long-anticipated death of a beloved and elderly grandparent. Even superb coping abilities cannot alter the finality of death. The survivors' helplessness and total inability to control the event may be what make bereavement particularly stressful. Understanding the nature of the bereavement process and why it is so long and difficult may make it easier for those who are experiencing it to cope.

Health care providers and institutions have a professional obligation to help families as they work through the painful and stressful process of bereavement that begins as the patient is dying, and continues after the death. The focus of this booklet is on the role of health care professionals in lessening distress, helping prevent pathological outcomes, and assisting the bereaved toward a satisfactory outcome. It offers information about bereavement reactions in adults and children and practical guidance on professional and organizational behaviors to increase the well-being of the family and others close to a dying or recently deceased person. For health professionals, such an understanding is needed to provide ongoing support and information to the bereaved and to recognize the red flags that should trigger referral to a mental health professional. ***Mental Health Professionals and the Bereaved*** discusses interventions by mental health workers for bereaved people who are unable to resolve their loss satisfactorily.

ADULT REACTIONS TO BEREAVEMENT

Everyone assumes that sadness accompanies the death of a loved one, but the bereavement experience contains a much broader range of emotional reactions and behaviors. These can be upsetting if they are unanticipated, appear inappropriate, or are misunderstood. For example, survivors are often angry toward the deceased for dying and "deserting" the family. It is common to feel angry at doctors (and guilty and angry at oneself) for not having done more to forestall death or make the dying person more comfortable, even when the bereaved know intellectually that nothing more could have been done. Knowledge about the various processes and outcomes associated with bereavement is likely to help avert the misunderstanding that can make the experience more difficult.

The first systematic study of bereavement was conducted by Erich Lindemann in 1944. He described uncomplicated grief as a syndrome with a predictable course and distinctive symptoms, including (1) somatic distress (physical symptoms), (2) preoccupation with the image of the deceased, (3) guilt, (4) hostility, (5) loss of usual patterns of conduct, and, in some people, (6) appearance of traits of the deceased (such as mannerisms or symptoms associated with a prior illness). Since that time, numerous clinicians and researchers have sought to corroborate these observations and to describe the grieving process in adults.

It is now generally agreed that:

The bereavement process is long, much longer than popular American notions would lead us to believe. Although, for many people, the worst is over within a year, evidence suggests that for some people the second year is more difficult than the first. For many people, the process may take several years.

The bereavement process does not necessarily progress in an orderly fashion, that is, people do not move systematically from one well-defined stage to another. Instead, they tend to move back and forth between what might be best described as overlapping and fluid phases.

Individual variation is substantial. People differ in how fast they recover and how they express their grief. Specific manifestations of grief depend on the personality and past experiences of the bereft person, cultural norms and expectations for behavior, the relationship with the deceased, the nature of the death, and the social milieu of the bereaved person.

Many emotions and behaviors that might be judged abnormal under other circumstances are common following bereavement. Nevertheless, some signs and symptoms may indicate serious problems that deserve the attention of a qualified mental health professional. However, the line between normal and abnormal (or pathological) is difficult to draw.

Anniversary reactions are common, even after the bereavement process is completed, in the sense that one is again able to function and take pleasure in life. It is typical to experience new waves of grief around holidays, important family events, and the time of year when the death occurred. These anniversary reactions may become briefer as time goes by, but they may never entirely disappear.

The Phases of Bereavement Reactions

The most immediate response following death, regardless of whether the loss was anticipated, is shock, numbness, and a sense of disbelief. Because the reality of the death has not yet penetrated awareness, survivors may appear to be holding up well and to be quite accepting of the loss. This numbness usually turns to intense feelings of separation and pain in the days and weeks after the funeral. One psychiatrist describes this phase in the following way:

> The absence of the dead person is everywhere palpable. The home and familiar environs seem full of painful reminders. Grief breaks over the bereaved in waves of distress. There is intense yearning, pining, and longing for the one who has died. The bereaved feels empty inside, as though torn apart or as if the dead person has been torn out of his body (Raphael 1983).

During this phase, the bereaved frequently

report illusions and misperceptions, such as seeing the dead person in the street and dreams in which the deceased is still alive. Eventually, these searching behaviors begin to decrease, but when the lost person fails to return, despair sets in. Depressed moods, difficulty in concentrating, anger at the deceased for dying, guilt about what might have been done to avoid the death, irritability, anxiety, restlessness, and extreme sadness are common during this time. Even the best-meant offers of comfort and support are often rejected because the grieving person is so focused on the deceased.

Dramatic and rapid swings from one feeling state to another are also typical of the early aftermath of bereavement. Avoidance of reminders of the deceased may alternate with deliberate cultivation of memories for some time. Gradually the death begins to be accepted. However, survivors may be intellectually aware of the finality of the loss long before they emotionally accept the truth. Depression and emotional swings are characteristic of most people for at least several months and often for more than a year following bereavement. Eventually, the survivor is able to recall memories of the deceased without being overwhelmed by sadness or other emotions, and is ready to reinvest in the world.

Health care providers are likely to find recently bereaved patients presenting with a host of physical symptoms. The functioning of all major bodily systems is altered during times of stress, including grief. Changes in the endocrine, immune, autonomic nervous, and cardiovascular systems are common. Although documented by many researchers, the health consequences of these changes are not yet established. Physiologic responses that begin as adaptive may sometimes become maladaptive and eventually deleterious to health if they continue too

long or become too extreme. The notion that a normal adaptive physiologic reaction can become unregulated and lead to illness is consistent with modern views of the pathogenesis of some autoimmune diseases.

A number of case studies appear to link grief and specific diseases such as various forms of cancer, heart disease, and ulcers (for example, Schmale and Iker 1965; Greene 1965). Establishing causal connections is difficult because of statistical problems and the low base rate. It seems more reasonable to consider bereavement a nonspecific stressor that triggers multiple changes which, in people who are vulnerable because of genetic predisposition or past or current illness, might lead to disease.

Quite apart from actual disease, recently bereaved people frequently report physical complaints such as pain, gastrointestinal upset, sleep and appetite disturbances, lack of energy, and other "vegetative" symptoms that at another time might signal the presence of depression. Especially in the elderly, these grief-related symptoms may be misdiagnosed as organic dysfunction if health professionals are not aware of bereavement reactions and the history of the particular patient.

Behavioral changes accompany these physical complaints and emotional upset. The bereaved person may appear slowed down at one moment and restless and agitated the next. Crying and tearfulness are common following a recent loss. When emotional despair sets in, the bereaved may lose interest in the outside world and cease normal activities, including such relaxing pastimes as watching television or listening to music.

Certain risk-taking behaviors may intensify or appear for the first time. Smoking, drinking, and drugtaking are common, especially among people

who were engaged in those behaviors to some extent before the loss. Altered eating habits (over- and under-eating and changes in the kinds of foods consumed) are also common expressions of depression that can be harmful, particularly for diabetics and others whose diets need to be carefully controlled. Behaviors such as these can be indirect expressions of grief that may eventually comprise a person's health.

Finally, bereavement often precipitates changes in interpersonal relationships in the family and in one's broader social network. Family roles are likely to shift after the death of a member. Bereft parents, for example, may be less emotionally available to their children because of their own grief, compounding the children's sense of loss.

Outside the family, the bereaved not only see themselves differently in relation to others, but are likely to be perceived in a new way. For example, suddenly thinking of another as a "widow" may evoke particular stereotypes or expectations, resulting in certain qualities being arbitrarily ascribed to the person.

The nature of these interpersonal changes depends largely on the relationship that was lost and, sometimes, on the nature of the death. These changes are also powerfully influenced by the bereaved person's age and sociocultural context. For example, a middle-aged widow or widower may find social life greatly curtailed because people tend to socialize in couples. Elderly people may find that most of their friends and relatives have died; especially when one is upset and elderly, making new friends can be difficult. Parents who have lost their only child may no longer fit comfortably with other families. Thus, social isolation and loneliness are common, often long after the bereavement.

The End of the Bereavement Process

A healthy bereavement process can be expected to end with recovery of lost functions (including taking an interest in current life, hopefulness, and the capacity to experience gratification), adaptation to new roles and statuses, and completion of acute grieving. Both favorable and unfavorable outcomes along several dimensions can be identified.

One of the most important dimensions is time. Despite the popular belief that the bereavement process is normally completed within a year or less, data from systematic studies and from clinical reports confirm that the process may take considerably longer for many people and still be considered "normal." The length of time *per se* does not distinguish normal from abnormal grief, but rather the quality and quantity of reactions. A precise endpoint cannot be specified.

Just as individuals vary in their reactions to grief, so too do they vary in outcome. What may signal a healthy recovery for one individual may be a sign of continuing difficulty for another. For example, readiness to invest in new relationships does not always indicate completion of or recovery from grief. A seemingly quick remarriage or a decision to have another child after one has died may reflect a sense of hope or strength in one case, whereas in another such actions may stem mainly from a wish to escape grief.

For some, bereavement provides an opportunity for personal growth that might not otherwise have occurred. Widows who had very traditional marriages, for example, may be forced to take on new roles and acquire new skills following the death of a husband. Being able to rise to these challenges successfully may leave a widow with a greater sense of

competence and independence than when she was married (Silverman 1982). Some have observed that bereavement can lead to heightened creativity, noting that numerous successful artists, writers, and musicians experienced painful losses.

Some people appear to be particularly vulnerable to poor mental or physical outcomes. For example, it has commonly been noted that 10–20 percent of the bereaved continue to exhibit depressive symptoms after 1 year (see, for example, Bornstein et al. 1973; Clayton and Darvish 1979).

Those Who May Be at Risk Following Bereavement

Because of their particular life situations or personal characteristics, some people have been found to be more vulnerable than others following the death of someone close. Awareness by health care personnel of patients who belong to one of the more vulnerable population groups will permit extra attention to monitoring the progress of bereavement.

In general, children are more vulnerable than adults. The gender and age of bereaved individuals, the nature of their relationships with the deceased, the nature of the death, and certain behaviors and social situations that appear soon after the death may affect how well the bereaved person ultimately fares.

Following the death of a spouse, widowers are more likely to die than are men the same age who have not lost their wives. This increased risk for premature death, which is characteristic for men up to age 75, seems to persist for many years unless the men remarry. Among widowers who remarry, the likelihood of dying prematurely is no greater than for nonwidowed married men the same age. It is not clear, however, whether marriage itself pro-

tects against ill health in bereaved men or whether their good health permits remarriage. Increased risk of premature death in the first year does not seem to characterize women who have lost their husbands, although there is some evidence for higher death rates in the second year following bereavement. Widows are much less likely than men to remarry because fewer single men are available (Helsing et al. 1981, 1982; Clayton 1982). This may heighten widows' vulnerability to some other stresses, including social isolation and financial problems that may require major alterations in lifestyle.

Although hypotheses abound concerning the relationship between bereavement and the subsequent development of particular diseases, the evidence is generally weak. What does seem clear, however, is that people who were physically or mentally sick before bereavement are likely to be sicker afterwards.

The stress of bereavement appears to exacerbate preexisting physical and mental disorders and may also precipitate or exacerbate certain dangerous behaviors. For example, among widowers, there is an increase in the relative risk of death from accidents, cardiovascular disease, and some infectious diseases. Widows have an increase in the relative risk of death from cirrhosis, indicative of heavier drinking following loss. Alcoholics have a high suicide rate shortly after bereavement.

Not only does each type of relationship (spouse, child-parent, sibling) have a different meaning during life and hence a different impact after death, but the nature of the particular relationship may influence the course of bereavement reactions. The literature on conjugal bereavement is replete with data indicating that individuals who had highly am-

bivalent relationships with their spouses fare worse following bereavement than people whose relationships were less conflicted (Parkes and Weiss 1983). It appears that ambivalence—the simultaneous presence of positive and negative feelings—heightens the already common feelings of guilt following the death of a close person and complicates the emotional grieving process. Also, excessively dependent people, for example, spouses who cannot (or fear they cannot) function independently, do poorly following bereavement (Parkes and Weiss 1983; Lopata 1973).

In terms of the nature of the death, it has frequently been hypothesized that sudden death is more traumatic for survivors and leads to poorer outcomes than deaths that are anticipated. Unfortunately, this has not been well studied and many different definitions of "suddenness" have been used. While common wisdom holds that time to say goodbye and to express love will facilitate grieving by lessening later feelings of anger and guilt, the moment of death is always a shock no matter how much warning has been given. And although some warning about an impending death may facilitate grieving, a very lengthy terminal illness produces its own stresses and strains that may complicate the grieving process. During a prolonged illness, families are more likely to witness suffering and sometimes dramatic personality changes in the patient that may heighten feelings of anger toward health professionals and guilt for not having done more (even if there was nothing more that could have been done) to ease the dying process. If normal social life has been greatly curtailed during a long illness, it can be difficult to reestablish friendships and activities after the death. The bereaved under these circumstances may suffer from substantially diminished social support.

One type of death that clearly leaves survivors more vulnerable to long-term difficulties is suicide. Typically, more psychological distress is experienced by family members following death by suicide than death from natural causes. Heightened anger directed at the deceased and guilt for not having been able to prevent the death, as well as true clinical depression, are more likely to occur and persist. This group of bereaved, especially children whose parent(s) committed suicide, are themselves more vulnerable to suicide (MacMahon and Pugh 1965; Birtchnell 1970; Lloyd 1980).

In addition to the risk factors that are present before bereavement or are related to the nature of the death, some elements of the early bereavement process itself can also affect ultimate outcomes. As noted earlier, the commonly observed increased drinking, smoking, and drug taking among the bereaved are obvious health risk factors. Individual symptoms during the early bereavement period that may also predict poor outcome include suicidal preoccupation (particularly after the first month) and morbid (excessive) guilt.

Bereavement researchers have devoted more effort to studying those factors that place people at risk for poor outcomes than to identifying factors that may be especially helpful to the bereavement process. However, considerable evidence has accrued showing that social support has a positive effect on general health status and may serve as a protective factor to buffer or modify the impact of adversity on both the mental and the physical health of the individual. Conversely, perceived lack of social support is one of the most common risk factors cited in the bereavement literature. The perception by the recently bereaved that no one is around to talk to or lean on appears to be a reliable

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predictor of poor outcomes (Parkes and Weiss 1983).

Need for Professional Intervention

Although bereavement is stressful for virtually everyone, it is important to reiterate that most people are able to move through the process without specialized professional help. Some people, however, are so predictably vulnerable that they should be monitored closely. These include adults who have a history of depression or alcoholism, are bereaved because of suicide, or have sustained multiple losses within a short time. Signs that help may be needed from a mental health professional include persistent suicidal thoughts and fantasies and a sense of being stuck in one's grief or unable to grieve.

CHILDREN AND BEREAVEMENT

An estimated 5 percent of children in the United States lose one or both parents by the time they are 15 years old (Kliman 1979). The many children who lose siblings, friends, or grandparents must also confront the reality of death and the painful and often frightening emotions associated with bereavement. Bereaved children may be particularly vulnerable to physical and psychological sequelae in both the immediate mourning period and over the longer term. Specific reactions are likely to be influenced by the child's level of cognitive and emotional development when the death occurred.

Health professionals who cared for a deceased parent or sibling and who are in continuing contact with the family are in a particularly good position to help parents understand and interpret their bereaved children's behavior. Family physicians and pediatricians who have a long-term relationship with bereaved families are also well positioned to respond to requests by parents for advice in dealing with their bereaved children, and to observe children over the course of bereavement to ensure that needed intervention takes place. To perform these functions, health professionals need to know how children react to and express grief, their fears and fantasies, and which children are at greatest risk for poor outcomes.

Children's reaction to loss often do not look like adults' reactions. Many differences in behavior, as well as the special vulnerability of children, are due to immaturity and lack of well-developed coping

mechanisms. For example, a child who plays games of death or funerals, one who tells strangers on the street "my sister died," or one who resumes play as if nothing distressing has happened, is not behaving inappropriately. Rather, the child is trying to master the loss, test others' reactions to the event, or protect himself from emotions so strong they can be endured only for brief periods. Misbehavior or angry outbursts often are grief related. Furthermore, children are likely to exhibit these behaviors for many years after the loss.

Children's ability to work through bereavement and complete their mourning depends in part on their ability to distinguish between death and temporary separations. Before the age of 6 or 7, children do not generally grasp the notion that death is irreversible. After that age, most children understand the finality of death but may not regard it as inevitable, universal, or of immediate relevance to them. By age 11, nearly all children understand that death is inevitable and represents the end of the life cycle. Only at this point does the child begin to conceptualize the future in terms of potential losses (Bluebond-Langer 1978; Koocher, 1973). It should be noted that for children who are intellectually precocious or retarded these ages will vary. In addition, children with previous bereavement experience and those who are facing their own deaths are likely to have greater understanding at an earlier age.

There is some theoretical disagreement about the implications of these stages of understanding for the outcome of childhood bereavement. In the past, some experts asserted that because very young children do not understand death and lack the capacity to mourn in a manner analogous to adults, they are unable to complete the process and are likely to have problems for the rest of their lives. A

substantial body of research now demonstrates that even very young children are able to grieve and make use of family supports to cope with loss. The chief difference between bereft children and adults is in the way they manifest their grief and in the children's need to rework and reintegrate understanding of the loss as they develop and are able to comprehend the event at new levels. Thus, although bereavement may render young children vulnerable, long-term problems are neither as frequent nor as inevitable as was once thought. How a young child fares after sustaining a major loss will depend in large part on the adequacy and availability of supportive adults.

While adolescents are thought to have the maturity to experience sustained pain and complete their mourning, they have a special vulnerability because they are simultaneously experiencing the normal developmental turbulence of adolescence. This already confusing time in life can only be made more disturbing if the adolescent must deal with the death of a parent, sibling, or peer through illness, or the shock of a violent death by suicide or accident.

Children's Fears, Fantasies, and Behavior

Immediately following bereavement, children are likely to feel sad, angry, and fearful. Depending on their age, they may have eating, bowel and bladder, or speech disturbances, and also commonly develop sleep disturbances. They may become withdrawn or excessively caregiving.

Certain fears and fantasies are likely to occur after a child loses a parent or sibling. Adults can be helpful in dispelling or calming these emotions. Some children fear that they caused the death, that they too might die, that the dead parent or sibling

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will return to seek revenge, or that the surviving caretaker will die and they will be abandoned. Children may see themselves as helpless and vulnerable, or as hostile and destructive, and use primitive defense mechanisms such as denial, aggression, and idealization in coping with their loss. Three questions, whether articulated or not, commonly occur to children who have lost a parent: Did I cause this to happen? Will it happen to me? Who will take care of me now?

School behavior and achievement frequently deteriorate after death of a parent or sibling. Several studies show that poor academic performance and decreased interest in school activities continue for up to 6 years after bereavement (see for example Black 1974; Elizur and Kaffman 1982; Lifshitz 1976). Delinquency has sometimes been linked to bereavement among adolescent boys, and some observers report that girls turn to sexual relationships for comfort and reassurance (Raphael 1983).

Reactions to birthdays and holidays and to anniversaries of the death can be a normal part of the grieving process in children, as in adults, for many years. But children, in contrast to most adults, tend to overtly rework their grief as they gain maturity and coping skills. Thus, children's reactions are likely to be out of synchrony with those of the adults around them—initially they may appear to have "gotten over" the loss too quickly; year later, when the adults have resolved their grief, children may be regrieving in a renewed effort to master the loss.

Children at Risk for Poor Outcomes

Although many retrospective studies have concluded that bereaved children are at increased risk

for physical and mental illness for the rest of their lives, a thorough review of the literature does not support that notion. Natural development and circumstances following bereavement may help children be more resilient. As a group, children do appear to be more vulnerable than adults, but many factors can intervene to reduce the chances of life-long problems (Bowlby 1980). This area needs further study.

Many factors, other than developmental stage, increase the chances of a child suffering excessively prolonged disturbances after the death of a parent. As with spousal bereavement, if the relationship with the deceased parent was one of hostility, ambivalence, or overdependence, the child may view himself as tiny and helpless or may idealize the dead parent. Such attitudes make the resolution of grief less likely.

The relationship between the gender of the deceased parent and that of the child has been studied with contradictory results. While some have found that special anxieties develop when the same-sex parent dies, epidemiologic evidence indicates that the most problematic losses are the death of the mother for a girl under 11 years old, and the death of the father for adolescent boys.

Other factors that increase the risk of psychological morbidity include excessive dependence on the child by the surviving parent, changes in environment (moving to a new house, disruption of routines, inconsistent discipline, etc.) after the death, parental remarriage to someone with whom the child does not get along or who is unsupportive, sudden death, and homicide or suicide.

For children, like adults, it is difficult to draw the line between normal and abnormal responses to bereavement, and to distinguish symptoms that call

for intervention by a mental health professional from those that are part of the long, painful, but expected experiences of grief. The death of a parent or sibling is a loss of such profundity that some reactions should be viewed as "normal" that might be considered pathologic in less traumatic circumstances. On the other hand, because it is so upsetting, some clinicians recommend time-limited intervention for *all* children who lose a parent. Others have tried to identify danger signals that should trigger a referral.

As with adults, the intensity and duration of grief reactions often distinguish normal from pathologic responses. Responses that should cause concern include persistent anxieties, sleep disturbances, blame and guilt, continued hopes for a reunion, persistent suicidal thoughts and behavior, patterns of overactivity with destructive outbursts, compulsive caregiving and self-reliance, euphoria with depersonalization, and identification with the deceased. Other signs are being unable to speak of the dead parent, exaggerated clinging to the surviving parent, apparent absence of grief, resistance to forming new attachments, complete absorption in daydreams, prolonged dysfunction at school, and delinquency.

ROLES OF HEALTH PROFESSIONALS WITH THE BEREAVED

Roles Before Death

Since more than 80 percent of deaths in the United States occur with several weeks' warning, health care institutions and caregivers are usually in close contact with families before the death. This period offers opportunities for making the patient and family as comfortable as possible during this difficult time, for facilitating a smooth separation from a dying patient, for helping relieve survivors of the guilt that often accompanies bereavement, to provide crucial information about the impending death, and begin to talk about bereavement reactions.

Although hospitals are widely perceived as bureaucratic, technologically oriented institutions, they have made striking improvements in the care of dying people and their families. This has come about in part as a response to evident public desire for more attention to the needs of those undergoing bereavement, and in part because of an increased acceptance of responsibility by institutional managers and health professionals. Humane considerations and compassion for those in need have extended responsibility beyond the patient to those acutely affected by the death, and new professional norms have developed to encompass this sense of responsibility.

These developments have occurred in the ab-

sence of third-party reimbursement for many of the supportive services that are today provided. Reimbursement is also lacking for many of the activities recommended in this booklet.

Gravely ill patients are often in the care of a team of professionals, and families usually seek assurance and information from doctors and nurses. It is important that one health professional be identified as having overall responsibility for patient care and for support and information for the family. That person most often is a physician. In addition, the patient's primary care physician before hospitalization should remain informed about the patient's status and respond to the family's need for reassurance and information.

Because families may feel more at ease with a nurse or find it difficult to understand information given by a physician, the primary nurse should be present when relatives are told that an illness may be in its final stage or when medical or surgical problems are discussed. The nurse can then answer followup questions and clarify information.

Health care professionals and hospital policies can facilitate the relationship between patients and those close to them in a number of ways. Communications between the patient and the family are helped if both are conversant with the diagnosis, treatment, and prognosis. Hospitals can facilitate communication by reducing or eliminating restrictions on visiting and by reducing the intrusiveness of medical procedures. Physicians and nurses, whose responsibilities extend beyond the dying patient to the well-being of the surviving family, need to understand that saying goodbye is important. Individuals should be allowed as much time as they wish with the patient. This may also help diminish the sense of guilt that so often ac-

companies bereavement. Guilt is also lessened if family members participate in decisions, and if physicians and nurses assure families that the medical staff have done the right thing for the person who died.

Finally, health care professionals should protect family members from becoming so worn out that they have no reserves left to cope with death when it occurs. Families should be encouraged to take time away from the bedside. Variations in tolerance for painful sights, smells, and sounds and in coping abilities should be understood. Health care professionals should try to accommodate the needs of individual family members as flexibly as possible.

Practices Around the Time of Death

Health care institutions are becoming increasingly responsive to people's needs around the time of death. To help families, institutional policies and health care personnel should allow relatives to be present at the time of death, and alone in the room after the patient dies. If relatives are not present, someone who cared for the patient and is known to the family must promptly inform them and ensure that the body is not removed until the family has seen it.

Preparing the bereaved for the grieving process by talking about the emotional and physical reactions they can expect will lessen their anxiety as these reactions are experienced (Macon 1979; Silverman 1982). It can also be helpful to offer to meet with relatives later to answer questions. Social workers may be especially helpful with some of the immediate practical problems of bereavement regarding funeral arrangements and legal and financial questions.

After the death of a patient, families are sometimes faced with a request for organ donation or autopsy. Although reservations about giving permission should be respected, it is reasonable for physicians to emphasize the positive aspects of helping others. Autopsy sometimes helps families accept their loss and assuage guilt feelings by pinpointing the cause of death. Thus, if an autopsy is performed it is important to discuss the findings with the family and answer their questions.

The Special Problems of Sudden Death

Sudden death can be especially shocking for relatives because it precludes the possibility of preparation. Health professionals should be particularly aware of the needs of these people, because in the immediate aftermath of the shock they are unlikely to be able to ask the questions they need to have answered. At the Children's Hospital National Medical Center in Washington, DC, for example, when a critically ill or dead child is brought in, some staff take responsibility for supporting parents while others attend to the child. This delineation of responsibility not only ensures parental support, it also reduces staff stress by making clear what each person's role is and not expecting anyone to be responsible for handling the entire crisis.

The death of an infant or newborn creates a situation that may need special attention. The parental guilt that inevitably follows the death of a child, especially from such causes as sudden infant death syndrome, can be diminished by authoritative medical information. Parents should be allowed to see or hold stillborn infants or babies who die shortly after birth (Cohen et al. 1978; Keller et al. 1981). When cultural or religious customs prohibit

parents from seeing their dead infant, or when devastating malformation makes viewing undesirable, it is particularly important for the parents to talk to staff who cared for the infant. The parents need confirmation that the infant really existed.

Some sudden deaths—accidents or natural disasters—take place outside of hospitals. The way families are notified and the nature of the early support they receive may have significant consequences for the course of bereavement.

Continuing Responsibilities of Health Professionals and Institutions

The death of a patient does not herald the end of health care professionals' or institutions' responsibilities to family members. The relationship between a physician and a terminally ill patient's family can become quite intense, having developed during a time of family vulnerability and anguish, often over a prolonged period before the death. Physicians and other health professionals should not inflict another loss on the bereaved by walking out on them after the death.

This is not to suggest that the physicians and others who cared for the patient must engage in long-term counseling with the family, or even be the one(s) to monitor the family's progress. In fact, the recently bereaved sometimes prefer to interact with someone who was not intimately involved during the terminal period because this allows them to "tell their story" as they see it without fear of contradiction. On the other hand, questions often arise after the death about the nature of the illness or treatment (including what else might have been done) and about family members' bereavement reactions. It is most important to make clear to the

family that support will be available when needed and either to provide that support oneself or arrange for it with another staff member.

Primary care physicians who did not personally take care of the deceased have an important role too. History-taking should routinely include questions about major life changes, including bereavement. Responses to such questions can open up discussion, allow the physician to describe the bereavement process, and initiate monitoring of the patient.

Long after the death, the family may have additional needs for information and reassurance. Remarks such as "He's better off this way" or any implicit or explicit criticism of family management of the patient should be avoided. Rather, health care professionals should respond to the expressed concerns and needs of the bereaved, provide assurance that grief reactions are normal, and be able to refer the bereaved to appropriate community or professional services as desired or required.

Although the training of health professionals differs substantially by discipline, such that some are better equipped than others for certain tasks, there is also substantial overlap. Physicians, nurses, social workers, psychologists, and pastoral counselors can all be helpful. In some cases, the choice of professional obviously depends on the nature of the problem at hand, but in other cases the choice may be appropriately based on the individual qualities of staff members and their availability.

All health care professionals should be aware of variations among ethnic groups in the degree to which emotional distress is manifested in physical symptoms. Somatization is common among some ethnic minorities, but persistent somatic complaints usually indicate a need for help from mental health

professionals. Other indications that mental health intervention may be needed include patterns of increased illness, greater smoking and drinking, and difficulty in maintaining social relationships. In children, repeated hostile or regressive behavior and deteriorating school performance signal a need for help. If such symptoms are noted during a telephone call, the individual should be given an appointment. Referrals should not usually be made on the basis of a telephone call.

CAUTIONS ABOUT THE USE OF MEDICATIONS FOR BEREAVEMENT REACTIONS

Although medications are frequently prescribed to reduce anxiety and insomnia and sometimes for depression-like symptoms, there is considerable controversy among physicians about the appropriateness of medication for grief reactions. No controlled studies have been conducted to test the efficacy of these drugs in bereaved populations.

Probably no other class of drugs is used more for grief reactions than hypnotics, since the bereaved typically complain of insomnia. Although sleeping pills may provide some symptomatic relief, they should be used cautiously, if at all, for short-term assistance and under close supervision to avoid habitual use and unwanted daytime side effects. In addition, since a common bereavement reaction is increased alcohol consumption, patients should be explicitly counseled about the dangers of combining alcohol and sleeping pills.

During the early weeks of grief when subjective distress is likely to be the greatest, some physicians prescribe benzodiazepines to relieve symptoms of anxiety, fear, tension, "stress," or psychic pain. Some clinicians have begun prescribing antidepressants to relieve the depression-like symptoms such as sadness, hopelessness, and other complaints that are common in the early phases of grief. However, the efficacy of antidepressants for grief reactions has not been studied, and such use is not currently approved by the Food and Drug Administration.

Although anti-anxiety drugs are known to reduce acute stress and situational neurotic reactions, and antidepressants relieve episodes of depression, their use is controversial during the early phases of the bereavement process for normal grief reactions. Many physicians believe that it is inappropriate (and perhaps even ultimately harmful) to interfere with normal grieving. They argue that the use of drugs to reduce distress will inhibit the adaptive value of grief work, and that failing to grieve or suppressing grief predisposes individuals to later mental disorder or medical disease (Morgan 1980). Others believe that such drugs may help relieve discomfort, promote better coping, and protect the individual from overwhelming reactions. However, even advocates of psychopharmacy caution against the overuse of drugs, especially over time. "The final resolution of loss is better accomplished by psychological help than by the use of drugs. Although drugs may be helpful in treating . . . the bereaved, their use is adjunctive, symptomatic, and limited in time" (Hollister 1972).

Anxiety and depression in the early aftermath of a major loss are normal. As long as these symptoms remain within the normal bounds of intensity and duration, they probably should not be treated with medication. A thorough clinical evaluation should be conducted before initiating drug therapy. Furthermore, great caution should be exercised when prescribing drugs for bereavement reactions. Most of these drugs can be habit-forming, and none mix well with alcohol. Particularly among the elderly, many of these drugs (especially benzodiazepines) can impair coordination and general functioning. Alcohol consumption may be high among the bereaved. Suicidal thoughts in the early weeks of bereavement are common. For all these reasons, if used at all,

medications should be prescribed in the smallest possible dosages and quantities, patients should be well informed of the risks, and they should be closely monitored.

COMMUNITY RESOURCES

In recent years the number and variety of resources available to assist the bereaved has proliferated. Although they vary widely in their approaches, audiences, and personnel, they all share a common goal—to help bereaved people cope with a painful event. This section describes the various kinds of bereavement programs generally available across the country. A list of some national organizations that can provide information about local resources is also included in the appendix.

Bereavement programs cannot be neatly categorized because many combine several different elements. Some of the distinguishing features that may be especially important to consider in selecting a program include the training of the personnel who provide the assistance, particular characteristics of the clientele for whom the program is designed, and when the intervention occurs in the bereavement process.

Lay Versus Professional

Many programs are run by lay people who have themselves been bereaved. The theory behind the programs is that people who have been through the experience are particularly well situated to help those who are currently trying to cope with it because they understand their feelings and practical problems. These programs (variously termed mutual support, lay support, or self-help groups) typically

offer a lot of information about the bereavement process, emotional support, and practical assistance with such things as funeral arrangements, financial questions, and adjustment to new social roles. Such help may be offered directly in one–to–one encounters or in group meetings, or indirectly through literature prepared by the group.

Lay volunteers often are required to participate in some formal training before they are permitted to help others. Many groups employ professional advisors to assist in developing materials, training volunteers, and planning program strategies. Sometimes the groups operate under the broad health care system umbrella in such settings as hospitals, hospices, and health maintenance organizations. They may also be sponsored by churches and synagogues, other community organizations such as the American Association of Retired Persons, or be independent.

In general, the lay mutual support interventions are geared to the vast majority of people who are expected to proceed normally through the bereavement process. For those who appear to be stuck in their grieving or to have abnormal reactions, these groups are often a good source of referral to mental health professionals. A professional consultation can help to discern the difference between a grief reaction within normal bounds and one that has developed into clinical mental disorder.

In contrast with the people who run most lay support groups, mental health professionals (social workers, psychologists, psychiatric nurses, and psychiatrists) are more intensively trained and oriented to deal with issues of loss as these might affect functioning and levels of distress over time.

Psychotherapeutic interventions for the bereaved may be brief and time–limited—ranging from

about 6 sessions (often called crisis intervention) to 20 or 30 sessions—or it may be long term and open ended. Therapy may be offered to individuals, families, or groups of similarly bereaved people.

Many different theories guide psychotherapy with the bereaved. The type of help offered will depend on the patient's needs and goals as well as the practitioner's orientation. Despite differences in methods and approaches, mental health professionals and mutual support groups share common goals in working with the bereaved: nonjudgmental support, compassion, and a desire to help the bereaved person or family resume adequate functioning and a sense of well-being. Differences lie in the depth and scope of intervention. Whereas nontherapists may be proficient at helping those who are experiencing normal grief, they are not usually prepared to cope with extreme distress or those highly disturbed reactions that suggest underlying mental illness.

In addition to coping with the loss itself, bereavement may provide an opportunity for resolving old conflicts, enhancing one's self-image, and developing new and more productive ways of coping with stressful situations. These are the kinds of issues that mental health professionals are trained to deal with and are therefore more likely to be focused on in psychotherapy than in a mutual support context (Worden 1982).

Characteristics of Bereaved Clientele

The choice of program or professional depends in large part on the characteristics of the bereaved. In recent years, there has been tremendous growth in support groups to assist those who are anticipating death from particular diseases and for those who are

bereaved from particular circumstances. For virtually every major life-threatening illness, support groups offer help to the patient and/or his family. These groups tend to focus primarily on prebereavement support and offer much less assistance afterwards. Numerous programs are designed to assist people who have experienced various kinds of sudden and, especially, violent deaths such as sudden infant death syndrome, suicide, homicide, and automobile accidents.

Many bereavement groups offer support to widows; relatively few are designed specifically for widowers, children who have lost a sibling or parent, or adults whose elderly parents have died.

Timing of the Intervention

Many programs are designed to assist with "anticipatory bereavement," while others are geared to those who are already bereaved. Among the latter, some offer immediate assistance and others work with the bereaved starting a month or more after the death. The original widow-to-widow model included immediate one-to-one support followed by group support after a couple of months. Hospice bereavement services offer assistance to the patient and family beginning with the patient's admission to the hospice program and often continuing for as long as 1 year after the death has occurred.

The Impact of Bereavement Interventions

Despite the proliferation of mutual support groups and psychotherapeutic approaches to assist the bereaved, very little has been done to evaluate their effects. Formal research on the topic often suffers from methodologic problems including small

sample sizes and lack of control groups. Evaluation research is particularly difficult because programs and approaches are so varied, the clientele is diverse, and there is little agreement about what outcomes should be assessed and how to measure them. Little is known about which specific program elements are helpful or harmful. Nonetheless, the literature is replete with testimonials from individuals who describe how helpful programs have been. Subjective reports and the clinical judgment of health professionals suggest that for many people some assistance is useful in coping with the stress of bereavement. Having information about the nature of the process, nonjudgmental support, and encouragement do appear to be helpful.

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APPENDIX

Health care professionals should be aware of the variety of resources in their community in order to be able to make referrals for the bereaved who want or need assistance. The following list may be useful in terms of knowing the scope of mutual support programs and in determining their availability in particular communities. To find out about resources in your community the following may be particularly helpful: churches and synagogues, hospital departments of psychiatry and social services, State and local mental health departments, national organizations for particular diseases or kinds of deaths (to find out about local chapters and to get their literature), school personnel, community centers, and funeral directors.

POSTBEREAVEMENT MUTUAL SUPPORT GROUPS

For Widowed Persons

THEOS (They Help Each Other Spiritually)
Office Building, Suite 306
Penna Hill Mall
Pittsburgh, PA 15235

For young and middle-aged widowed persons; each chapter has a chaplain; 100 chapters nationwide.

Widow-to-Widow Programs

Hundreds of local mutual help groups and networks sponsored by churches/synagogues, YM/YWCAs, community mental health centers, family service associations, mental health associations, funeral directors associations, and freestanding community groups.

Widowed Person Service Directory lists about 400 groups nationwide. New Jersey Self-Help Clearinghouse lists 42 in State of New Jersey alone.

Widowed Persons Service
American Association of Retired Persons
1909 K Street, N.W.
Washington, D.C. 20049

Peer support and visitation to widowed persons; 135 groups nationwide; AARP-WPS provides consultation and training for leaders of new local groups.

For Survivors of Suicide

Seasons: Suicide Bereavement, Inc.
4777 Maniloa Drive
Salt Lake City, UT 84117

For families and individuals (including therapists, police, and work colleagues) who have lost a significant other by suicide; co-facilitators involved in support group discussions—a survivor and a professional; national organization.

Survivors of Suicide (S.O.S.)
c/o Fr. Arnaldo Pagrazzi, Chaplain
St. Joseph's Hospital
5000 W. Chambers Street
Milwaukee, WI 53210

For families and friends of suicide victims.

For Parents

The Compassionate Friends
P.O. Box 1347
Oak Brook, IL 60521

For bereaved parents; 325 groups nationwide.

Families of Homicide Victims
2 Lafayette Street
New York, NY 10007

For parents of homicide victims.

Mothers Against Drunk Drivers (MADD)
5330 Primrose, Suite 146
Fair Oaks, CA 45628

Open to all citizens; many are survivors of drunk driver caused crashes; many are relatives and friends of victims; national organization.

National Foundation for Sudden Infant Death (SIDS)
1501 Broadway
New York, NY 10036

For parents who have lost a child to crib death.

National Sudden Infant Death Syndrome Foundation
8240 Professional Place
2 Metro Plaza, Suite 205
Landover, MD 20785

For parents who have lost a child to crib death; national organization.

Parents of Murdered Children
1739 Bella Vista
Cincinnati, OH 45237

For parents of murdered children; recently established a new category of group—Survivors, for other relatives such as sibling, grandparent, and adult child of a murdered parent. 40 chapters nationwide plus contact persons.

VOLUNTARY ASSOCIATIONS (WITH SUPPORT GROUPS) AND MUTUAL HELP GROUPS FOR PATIENTS AND FAMILIES WITH LIFE-THREATENING ILLNESSES

Alzheimer's Disease and Related
Disorders Association
2501 West 84th
Bloomington, MN 55431

For caregivers of Alzheimer's patients.

American Cancer Association
777 Third Avenue
New York, NY 10017

- Man-to-Man: Peer visitation programs by partners of women who have mastectomies

- Reach to Recovery: Peer counseling by women who have undergone mastectomy
- Lost Chord, Anamilio, and New Voice Clubs: 260 clubs nationwide are members of International Association of Laryngectomies
- I Can Cope: A support group for cancer patients and their families

American Lupus Society
23751 Madison Street
Torrance, CA 90505

For patients and families; 100 chapters nationwide.

American Parkinson's Disease Association
116 John Street
New York, NY 10038

For Parkinson patients, their families and friends.

Amyotrophic Lateral Sclerosis Society of America
15300 Ventura Boulevard, Suite 315
P.O. Box 5951
Sherman Oaks, CA 91403

For patients and their families.

Association of Heart Patients
P.O. Box 54305
Atlanta, GA 30308

Candlelighters Association
2025 I Street, N.W.
Washington, DC 20006

For parents of children with cancer; 155 chapters nationwide. Newsletters of other publications for parents and adolescents as well as support groups.

Center for Attitudinal Healing
10 Main Street
Tiburon, CA 94920

Mutual help pen pal/phone pal program for children, parents, or other adults with life-threatening illness.

CHUMS
(Cancer Hopefuls United for Mutual Support)
3310 Rochambeau Avenue
New York, NY 10467

For cancer patients/survivors and their families and friends.

Committee to Combat Huntington's Disease, Inc.
250 W. 57th Street
New York, NY 10107

For patients and affected families; 29 chapters nationwide plus branches and area representatives in 44 states.

Coronary Clubs, Inc.
3659 Green Road
Cleveland, OH 44122

C.U.R.E. Childhood Cancer Association
315 Marion Street
Rochester, NY 14610

For children and families.

Cystic Fibrosis Foundation
6000 Executive Boulevard, Suite 309
Rockville, MD 20852

For parents of children with cystic fibrosis; national organization.

Gillain–Barre Support Groups
1305 Wyngate Road
Wynnewood, PA 19096

For victims of GB Syndrome.

The Lupus Foundation
11673 Holly Springs Drive
St. Louis, MO 63141

For patients and families; 70 chapters nationwide.

Make Today Count
P.O. Box 303
Burlington, IA 52601

For persons facing a life–threatening illness and their relatives and friends; 300 chapters nationwide.

Myasthenia Gravis Foundation
15 East 26th Street
New York, NY 10010

For myasthenics, relatives, and friends; 51 chapters nationwide.

National AIDS Network
729 8th Street, S.E.
Suite 300
Washington, DC 20003

Information clearinghouse for AIDS patients, friends, and families regarding resources in local communities across the country.

National Association of Patients on Hemodialysis and Transplantation
156 Williams Street
New York, NY 10038

For patients, their families and friends; 33 chapters nationwide.

National Head Injury Foundation
18A Vernon Street
Framingham, MA 01701

For families of head injured; 28 chapters nationwide.

National Hospice Organization
1901 North Fort Myer Drive
Arlington, VA 22209

For terminally ill patients and their families; more than 1,000 hospice programs nationwide.

National Multiple Sclerosis Society
205 East 42nd Street
New York, NY 10017

For patients and their families; 124 chapters nationwide.

National Tay-Sachs Parent Network
122 E. 42nd Street
New York, NY 10017

For parents of children with Tay-Sachs.

Parents of Prematures
13613 NE 26th Place
Bellevue, WA 98005

For parents who experience birth and hospitalization of premature or critically ill babies.

Phoenix Society
11 Rusthill Road
Levittown, PA 19056

Recovered burn victims work with severely burned people and their families; national organization.

SHARE (Self-Help Action and Rap Experience)
34 Gramercy Park
New York, NY 10003

For women who have had a mastectomy.

SKIP (Sick Kids Need Involved People)
216 Newport Drive
Severna Park, MD 21146

Helping families of children with various levels of medical instability care for their child at home; new organization.

Spina Bifida Association of America
343 South Dearborn, Suite 319
Chicago, IL 60604

100 chapters nationwide.

Stroke Clubs
7320 Greenville Avenue
Dallas, TX 75321

For those who have had strokes and their families; 312 clubs nationwide.

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